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# Accepted Manuscript

How to Establish Successful Research Partnerships in Global Health Palliative Care

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**How to Establish Successful Research Partnerships in Global Health Palliative Care**

To the Editor:

Research evidence is key for successful implementation of the World Health Organization (WHO) strategy to establish a public health approach to palliative care in low and middle income countries (LMIC).<sup>1</sup> Tackling inequity may be achieved in part by establishing palliative care as a global health discipline to generate the required evidence.<sup>2</sup>

Sub-Saharan Africa has been an exemplar in generating research evidence in order to underpin advocacy, education, access and quality improvement. This has been a strategic response to the high mortality in Africa associated with HIV and cancer, and the recent refocus of palliative care onto other non-communicable diseases (NCDs).<sup>3</sup> From a very low evidence base, the volume of original research is increasing rapidly. Over the past 15 years, the African palliative care evidence base has moved from exploratory comparative qualitative studies<sup>4</sup> to outcome measurement<sup>5</sup> and into trials,<sup>6</sup> costing studies,<sup>7</sup> and studies of novel populations such as those with drug-resistant tuberculosis.<sup>8</sup>

Establishing successful international research partnerships has been key to this success. In addition to a shared agenda of priority research questions for the region,<sup>9</sup> well-functioning sustained partnerships are needed to build capacity and deliver robust evidence. Given the inherent power imbalances that support research (i.e., palliative care funding sources and academic departments are mainly based in high income regions), careful consideration of the principles and practice of research partnership is essential.

At the recent African Palliative Care Association/World Hospice Palliative Care Alliance triennial conference held in Kampala Uganda, we convened an expert workshop on

“Research Partnership.” The conference was attended by 45 delegates from 17 countries. Following presentations from research leads from Africa and Europe, delegates developed consensus on a series of recommendations for successful international palliative care research partnerships.

*1) How to position oneself in LMIC as a research partner.* It was acknowledged that a minimum level of research training and exposure is required, and individuals should seek local opportunities to demonstrate their commitment to research activity. Conducting small scale unfunded local studies also is recommended to establish a research profile. Individuals interested in partnerships should also identify potential partners in high income countries (HIC) and state their interest in partnership. It was recognized that research leads in HIC need to be aware of potential partners in LMIC. Potential researcher leads in LMIC universities should identify postgraduate students who need to conduct research as part of their study. Potential LMIC leads also should identify ways to incorporate research activity into daily practice using existing patient cohorts and routine data exploitation.

*2) Agreement and communication.* The research question should be of mutual importance to all partners. The skills mix should represent partners from each participating country. Time to establish a relationship should be invested including face-to-face meetings, and shared expectations should be identified. Partners also should establish clearly how progress will be monitored and the required communication processes, and how arising problems will be addressed. The mutual benefits for each partner should be articulated (e.g., capacity, status, and adequate funds). Ownership of intellectual property, and agreement on roles in publications and presentations should be clear. Learning is a bi-directional process, and HIC partners must be committed to a concept of mutual learning and for identifying new and useful knowledge transferable in both directions.

3) *Dissemination*. In order to attract international donors, research partnerships should ensure that they demonstrate strong research impact and linkage between research, policy and practice. Dissemination strategies should ensure that they include relevant stakeholders for every partner and that activities are built in to ensure each partner benefits from the strategy.

4) *Challenges*. It was recognized that very few HIC funders allocate support to global health palliative care. LMIC partners recognized that the available limited resources are often allocated away from research even when partnership is established. In order to conduct research, funders require evidence of locally valid tools and measures, and it was acknowledged that these are not always available and partnership is sometimes required to establish tool validity prior to applying for research funding. Lastly, in terms of data collection, funding is required to ensure that responsibility does not fall on existing overburdened, underfunded and understaffed clinical services.

5) *Opportunities for HIC support*. Delegates supported the idea of HIC sending postgraduate students to LMIC to transfer skills and learning, and to encourage emerging researchers in HIC to engage in global health. HIC also should ensure that all grant applications include mentorship and teaching tasks to ensure that LMIC capacity is built. Lastly, they should be encouraged to publish findings in Open Access journals (or pay for open access) to ensure that findings are accessible.

We believe that these principles should serve as a point of reference to ensure mutually beneficial and successful partnerships. Investment of time and resources in such partnerships may not only ensure that research is delivered successfully, but also may move the state of science towards closing the gaps in palliative care equity experienced in LMIC.<sup>10</sup> Robust evidence is essential to achieving this, and is required by the World Health Assembly's Resolution on Palliative Care (2014). We also believe that lessons from sub-

Saharan African partnerships with HIC also may serve to assist those developing research in other LMIC, and to expand the scope and understanding of palliative care research in HIC.

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